Where the Doctor-Patient Relationship is Heading: Literary Perspectives

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The author of today's guest blog post is Dr. Anna Magdalena Elsner, a Swiss National Science Foundation Marie Heim-Vögtlin Research Fellow working at the Center for Medical Humanities at the University of Zurich. Her current project is entitled 'Palliative Pages'. Focusing on the history of modern palliative care in France as well as French end-of-life writing from the 1950s onwards, the project contextualizes the dual grounding of the 'palliative' in medicine and the humanities. She has previously written on Marcel Proust and the doctor-patient encounter in twentieth-century French literature and documentary cinema. In line with a 'critical medical humanities' approach, her research seeks to make the case that French literature and comparative cultural analysis could play a more important role in the Medical Humanities. Follow her on @a_m_elsner.

'Muzil spent a morning in the hospital having tests done, and told me he'd forgotten how completely the body loses all identity once it's delivered into medical hands, becoming just a package of helpless flesh, trundled around here and there, hardly even a number on a slip of paper.'[i] It is in these words that Hervé Guibert describes Michel Foucault's experience of being hospitalized for HIV/AIDS in early 1990s France. This is echoed by Clive Sinclair, who comments on the physicians treating him during his year of dialysis: 'In their eyes I am not a man, I am a patient. As such I am required to be good-humoured, stoical, dependent, and sexless.'[ii] These examples have broken away from Molière's physician-charlatans, Proust's priest-like father figures or the altruistic, unlucky scientist that is Tertius Lydgate in George Eliot's *Middlemarch*. Instead they are paradigmatic for the doctor-patient relationship in the latter half of the twentieth century, capturing the dehumanizing effects of Foucault's 'medical gaze' under which the therapeutic importance of the doctor-patient relationship is pushed to the margins of an all-powerful biomedical framework. In the foreground is the anonymity of the hospital setting paired with technical descriptions, patronizing discourses and a general distancing from and disinterest in the patient's experience of illness.

However, the end of the twentieth century also sees a proliferation of autobiographical narratives about illness and the end-of-life, thereby pointing towards a new interest in recovering the patient's voice. This might be connected to the rise of biomedical ethics since the Second World War and, as a result, the challenging of medical authority and paternalism with the aim to

empower patients. The establishment of patient advocacy and, more recently, patient safety organizations, together with concepts such as 'patient-centered medicine' and the late idea of 'health literacy' – in France chronic patients can gain a university diploma as 'patient expert'[iii]– bear testimony to a fundamental shift in the relationship. This is illustrated by the bedside reading the American author Joan Didion picks up when her daughter is hospitalized for a brain hemorrhage: 'I went to the UCLA Medical Center bookstore. I bought a book described on its cover as a "concise overview of neuroanatomy and of its functional and clinical implications".'[iv] The wide accessibility and heterogeneous resources of health information and the ways in which these reshape the doctor-patient relationship,[v] might be said to have been foreseen by the telling title of Anatole Broyard's posthumously published short story 'The patient examines the doctor'.[vi] The flip side of the rise of concepts such as patient autonomy or patient expertise is not only a paradigm shift with regard to the role assumed by the physician, but the 'patients as partners' approach also relies on the idea of an 'active patienthood'. As Jenny Diski has described in her memoir *In Gratitude,* this is not always an option:

> *This is one of the surprises of being cancered. I don't approve, but I don't have the energy to roll up my sleeves and find out everything there is to be found. The exhaustion makes me incapable, but there is also some absence of will to find everything out.[vii]*

The authors of a 2015 introduction to the medical humanities remark that the doctor-patient relationship 'is in trouble on both sides of the hyphen'[viii] – because doctor-patient encounters are often hurried, increasingly mediated by technology and take place in impersonal hospital settings. In recent years, it has been the doctors' voices and their dissatisfaction within increasingly bureaucratic institutions that have been coming to the fore.[ix] Deploring structural changes in medicine and testifying to an erosion of confidence in the future of the medical profession and the place attributed to the doctor-patient relationship rather than the impersonal practice of empathetic skills,[x] they echo what the French physician and writer Jean Reverzy has already in the mid-twentieth century described as the overwhelming 'fatigue' of the physician. The development of narrative medicine, the further integration of medical humanities courses in the medical curriculum, but also the development of subspecialties such as palliative care have been steps taken to counter these developments in order to advance towards more humanistic clinical care. Yet there are new challenges for both physicians and patients on the horizon in the age of genomic medicine: the role of the physician will gravitate towards technical expertise and/or will be shaped even more

significantly by the need to assist the patient in the information-gathering process. But the role of the patient will undergo a comparably fundamental shift as genetic predispositions – rather than an already developed disease – will play a role of growing importance.

Notes

[i] Hervé Guibert, *To the Friend Who Did Not Save my Life,* trans. by Linda Coverdale (New York: Atheneum 1991), p. 23.

[ii] Clive Sinclair, 'My life as a pig', in *Doctors and Patients: An Anthology* (Oxford: Radcliffe Medical Press, 2003), ed. by Cecil Helman, pp. 73-80 (p. 77).

[iii] The 'Université des patients' established in 2010 is part of the medical faculty Pierre et Marie Curie in Paris.

[iv] Joan Didion, *The Year of Magical Thinking* (London: Harper, 2006), p. 104.

[v] The importance of patients sharing information with fellow patients – and physicians drawing on these data – is illustrated by the international success of healthtalk.org.

[vi] Anatole Broyard, *Intoxicated by My Illness And Other Writings on Life and Death* (New York: C. Potter, 1992), pp. 33-58.

[vii] Jenny Diski, *In Gratitude* (London: Bloomsbury, 2016), p. 116.

[viii] Thomas R. Cole et al., *Medical Humanities: An Introduction* (Cambridge: Cambridge University Press, 2015), p. 37.

[ix] See, for example, Atul Gawande, *Being Mortal: Medicine and What Matters in the End* (New York: Picador, 2014); Seamus O'Mahony, *The Way We Die* Now (London: Head of Zeus, 2016); Haider Warraich, *Modern Death: How Medicine Changed the End of Life* (New York: St Martin's Press, 2017).

[x] See Leslie Jamison, *Empathy Exams: Essays* (Minneapolis: Greywolf Press, 2014).

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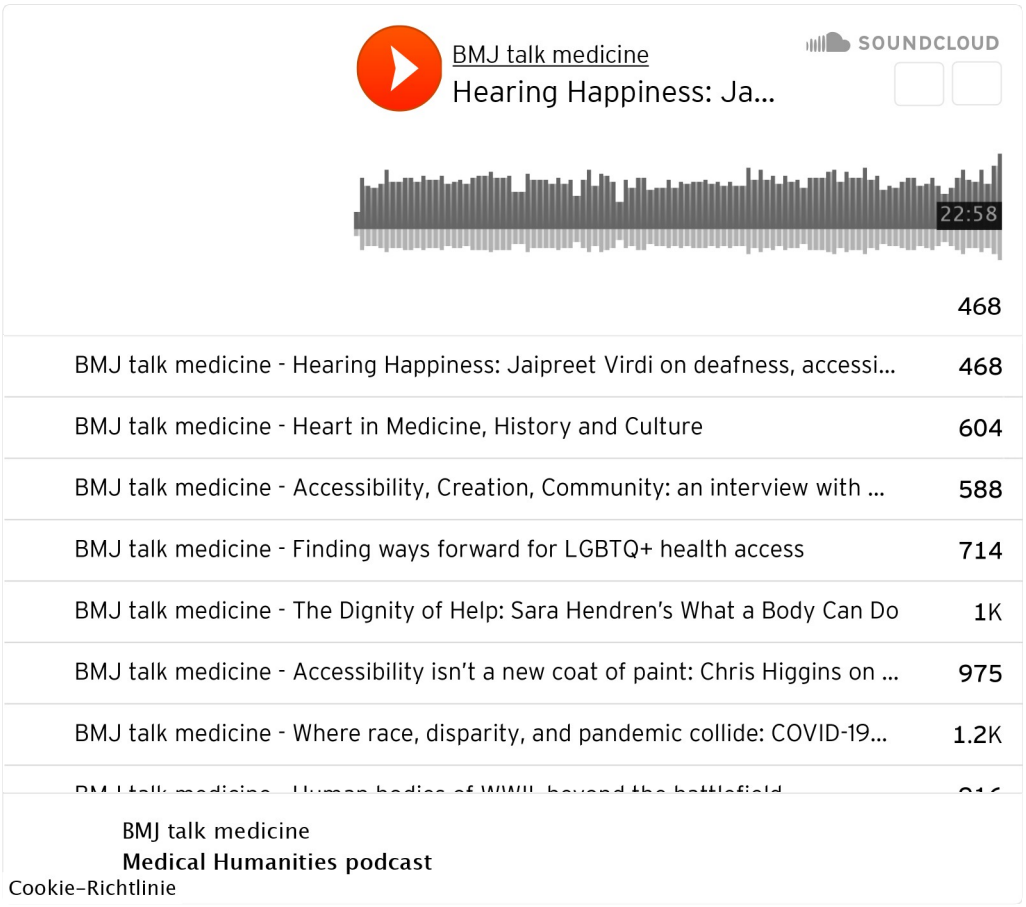

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